

GAC Medicaid Transition Residential Services Work Group  
1056 Woodbrook Conference Room, Dover  
April 23, 2015 1:30 p.m. – 3:30 p.m.

Present: Melinda South, Victor Schaffner, Bill Monaghan, Gary Mears, Laura Waterland, Kathie Cherry, Kimberly Reinagel-Nietubicz, Kyle Hodges, Terry Olson, Lisa Green, Tim Brooks, Frann Anderson, and Libby Cusack. Non-committee members in attendance included: Barbara Monaghan, Micki Edelson, and Pat Maichle.

Okay, let's go around the room for introductions, and please speak up for the recording, it's over here. Libby Cusack

Melinda South.

Lisa Green.

Kathy Sherry.

Fran Anderson.

Terry Olson.

Victor Schaffner.

Tim Brooks.

Laura Waterland.

Gary Mears.

And Guests

Mickey Edelson.

Pat Michael.

Okay, and let's go through the meeting ground rules, just to quickly go through these each week. The meetings are being recorded, so please announce your name when you speak, and make sure you speak up. One person talks at a time. Limit phone calls during the meetings. We are going to try to start and end the meetings on time. Stay on agenda. Do your homework prior to the meetings. Documents are being sent out via email. Guests may participate in the meetings but only committee members may vote. Next on the agenda is a transcript from last week's meeting. I don't know if everybody made it through the entire document or not, it was from my perspective quite interesting reading. But it was good to have. It was a lot of information with everybody's comments. And some words were missed or incorrect, names were missed or incorrect. I think to correct that document you could spend probably the full two hours on going through that document. So what I'd like to recommend and if anybody else has any other suggestions, if there's any significant issues with the document or changes that you would like to see, if you like to submit those via email to somebody who would like to volunteer to manage that document because I'm certainly not going to manage that document (chuckling). Otherwise, we are just going to leave it as is and move forward, so would anybody like to accept the changes and be responsible for that document? Since no one is looking up, I assume that is a no. We'll continue to ask, and if anybody would like to change their mind at a later time, just let me know. And we'll try to get that document if there are any significant changes that need to be made to that document, we'll try to get those submitted.

Yes

Fran. Would it be possible, if somebody wanted to change that document, could Vicki do that for us? If we emailed her the change?

She might. I think if there are substantive changes, you definitely want to go back and have some

change in the document. And I think she probably has it in a Word document so she should be able to make those changes but -

And we probably need to make sure everybody's aware of what's being requested.

Right

So maybe if they are sent to me and then I could forward this on to Vicki and get them out to everyone. So if you have any changes that you would like to see with the transcripts, you can send that information to me. Okay, updates on the action items from last week's meeting. I tried to track as many as I could and I missed some, but let's get through this list and I sent out an email earlier today, and I'm sure not everybody has a copy of it or had a chance to go through it, but Fran did send responses to the action items. So Fran I do you just want to go through this quickly?

Sure.

There aren't extra copies of the agenda, are there?

No

So these are the questions that I brought back to Jane that the committee had posed at our last meeting, so the first question that came up was how would shared living providers be assessed. Jane's response is that they will be assessed completing a self-assessment and the DVDS staff will do a look behind. It will probably be my staff or QI. Will a separate assessment be developed for shared living providers? The response is the shared living provider will use the same assessment as agency providers. If there are any agency type questions they will be removed from the shared living provider assessment form.

This is Libby. I was looking through those notes again from last week. Or for two weeks ago. Jane mentioned that she was looking to have a shared living provider join our committee.

I don't know if she has reached out to anybody but I'll ask her.

OK

Shared living arrangements again are formerly known as adult foster care.

Would you like to introduce yourself, Bill, and have it recorded?

Bill Monahan, Delaware people first.

Thank You.

Try again. The third question was, will out of state agencies providing supports to Delaware individuals need to complete the Delaware assessment or follow the process laid out in the state in which they operate, and the response is that the providers are qualified by Delaware to provide services for which the state pays, therefore the out-of-state agency will complete the Delaware assessment. Question four is what will be proof or evidence of compliance to the CMS rule. The response is, DDDS would welcome suggestions from the committee as to what they would consider valid proof based on the questions asked. Question five, will the transcripts of each meeting be provided to the group prior to the next meeting? At the time that the responses came back, the transcripts were already out. And Libby had referred to those a little bit earlier. Question six, can individuals living in a neighborhood home develop rules for the house that the group are in favor of, are contrary to the CMS rule? The responses the group cannot create rules that would not be in or compliant with the CMS rules. However, the establishment of house rules are acceptable if all individuals who live in the home have made an informed choice and all residents are in agreement. Validation that the residents themselves have determined house rules would be necessary. Question seven, will nursing homes caring for individuals supported by DDDS have to complete the assessment. The answer is no. This is not a home and community-based service. Question eight, should Homestead be reviewed or applied as in the 220 rule as proactive measure? The response is, DDDS will review this is part of their internal protocol procedure review. So as

everybody knows, DDDS will also be doing a self-assessment, and this issue will be part of our self-assessment for the state. Number nine, does the division (voices overlapping) so providers are doing their self-assessment to see if they are in compliance. We also have to look at our own policies and procedures within the state, within DDDS, and so the Homestead issue becomes a state issue.

This is Terry Olson. DDDS is going to be asking itself whether the two and 20 rule should apply? We're going to look at our policies around that I make a determination about whether or not we should apply that. We will look at that as part of our process to gather information.

Number nine, does a division director recommend any other assessments to be reviewed at the next meeting? I believe Jane sent out some other assessments including Pennsylvania and Hawaii. And the last one is, is DDDS aware of any assessments that have already been approved by CMS? And the response is, CMS does not approve assessment tools, they approve the transition plan. As part of their transition plan, Tennessee did submit their assessment tool. No statewide transition plan has been approved by CMS as far as the division director is aware.

This is Tim. Do you know if Tennessee got any feedback on their tool?

I don't know but we can find out.

This is Libby. Before we move on with the action item list I just wanted to point out a couple papers listed up here. And we can agree to use these were not. I was just looking for additional tools to try to keep our necks together. The first one over here to track action items. I know that they are going to be in the transcripts, but we can pick them out. It may be a little bit difficult. As we come up with action items, we are going to jot them down here. Tim volunteered to jot them down and we already have one here that we need to put up here. And then this one over here, as we go through the state assessments, if we all agree that we like a question, I was thinking that maybe we should just start making a note of these questions, what state, page number it is, so we keep that on a list. As we went through the documents last week, there are some topics that came up for discussion, and I think we need to get back and discuss some of these is little bit further. But I think it needs to be an agenda topic for some of these items because we need to put some time to some of these topics. So I went through the, the notes from our last meeting and tried to pull some of these things out. I don't remember who brought some of these up. And we can agree to add these to the next agenda item, if we agree to, or if not. But I pulled some of these things out from last week's meeting. Guardianship was brought up the impact, including some of the questions, answer options, besides yes no, not applicable, there were some other options out there. Assessment for provider agencies. Some states also created assessments for individuals living in the settings complete. Do we want to do that as well? What is considered valid proof or evidence of compliance? I think we talked about that several times. Do assessment responders include evidence, the documents or do they make a note of the document title page, etc. in their assessment. And choice of living arrangement questions. This came up towards the end of the meeting. How do we address choices. From people who have moved into facilities many years ago when there wasn't really a choice, and will get back to this. But I just wanted to let you know what we had up here. And she was going to try to keep track of that as we go along. And Kimberly is on the phone. Kimberly, I don't know if you announced yourself at the beginning of the meeting. I didn't but I can. I'm Kimberly (inaudible), Controller General's office.

And before we get back to the action item list, let's see, Kyle said she was going to be a little bit late to meeting today. And Jamie is out of town so she's not going to be here today. All right, so if we go back to the action item list, and I included it on the second page of the agenda. And Fran's added more of the action items to her list. That was a very good thing, so thank you Fran. The next action

item was for Terry Olson about the Council on quality leadership that we discussed last week. I don't know if any of you have checked your email in the last couple of hours, but I did send out what I found. Is a 29 page document, and I may have one I can pass around here. Libby you can keep that one if you wish.

Okay, and this is just another, this is a sample of questions similar to what we're going to be putting together for the Delaware assessment? Is that correct?

Yes.

And this is Terry Olson, I should identify myself. Basically CQL and Mosaic entered into a partnership.

Excuse me Terry, what's CQL?

That's the Council on quality leadership. Good question, Bill. They're a national accreditation agency that accredits service providers for persons with disabilities among others. OK? And I don't know that this was the final document. It's just a document I found, but within this partnership, they developed certain standards and then they had system questions, and I've heard Fran speak about systems. I'm a big systems person. So I think there's questions about our policies and procedures in place for ensuring this expectation. There's an example on that first page. And then there's practices, so both the questions on systems and practices, I would consider to be the equivalent of probes, as we talked about last meeting. And then I made note of some of the sections that might have some relevance to some of the criteria that we're looking at within CMS guidelines. So for example there's on page 1 through four, there's a list of questions on rights, and I think rights and responsibilities was something that was asked pretty generically and from my perspective, ambiguously. There's a very brief section, probably not specific enough on people have meaningful work and activity choices, that's on page 7 for anybody that's looking up. There's some questions on abuse, neglect and related protections, trending analysis and so forth. Some important questions on person centered plans and then some questions relating to due process for restrictive procedures.

This is Libby. I know I saw the email but I did not have a chance to read through it. If everybody could take a look at that document and then if it looks like something that we would want to add to an agenda, spend some time reviewing it or discussing it, at a future date. If somebody could let me know that, I'll add it to the agenda.

This is Terry again. The other comment I should have made was in the instructions they talk about prevalence, and I think it's a significant concept. For example, in the process of assessing an individual, you might find that a specific criteria hasn't been met, but you may find for the other four persons or three persons within the home, that it has been met. I think there should be some distinction made between an agency or facility or home that's totally out of compliance and one that may just be mostly in compliance, if that makes sense. So prevalence was the way that was approached within this document.

Alright, thank you Jerry.

Laura, you are going to research the density questions that came up last week.

Well, I wasn't quite sure why we needed to know(chuckling), because it came up in a conversation about the two and 20 rule that's in the DOJ (inaudible) for scattered housing.

I think the other item that came up was how many group homes -

Well dispersal is kind of, is a concept you see when you talk about zoning and fair housing. Not Medicaid standards. In Delaware the law has changed a number of years ago, at least for counties, if it's the way the statute reads, if it's a licensed state facility for 10 or less people they are considered to be single-family dwellings and there is no dispersal requirement. But I guess...

Sorry, this is Libby. What is a dispersal requirement?

You see them in other states sometimes. There used not as much anymore, where you can only build one, there used to be the distance limit, like you can't put two together. Two group homes together or facilities for people with disabilities. They have to be more than 1000 feet apart or whatever. In Delaware that was (someone coughing) for homes of less than 10. So it's not an issue. Okay. It's dispensed for homes with less than 10 people.

Yeah, they are considered to be single-family dwellings.

It doesn't mean that there can't be standards in place that are necessary to comply with the CMS guidelines in terms of making sure that the settings are integrated. Those are two different ideas. There have been litigation, there's a case in the Eighth Circuit out in Minnesota where a service provider for mental health for people in mental health wanted to build a large or increase the size of a development of housing that they had that was very much accommodated setting, and they were trying to argue that Minnesota didn't have the ability to impose any kind of restrictions on concentration based on integration ideas for the ADA. They tried to use it for housing and kind of justify that, and the court said basically it may be pretty twisted for Congress to allow somebody to use it for housing, which is an antidiscrimination provision to get around the ADA's requirement that there be community integration. So for purposes of this committee, I think we should be developing some questions to help address, I think the rule that people are concerned about is, we have a list of types of settings, in the CMS rule do not qualify as home and community-based settings, and one of them is, is there any other setting that has the effect of isolating individuals receiving Medicaid, and so I think part of what we might want to do in the questionnaire on the self-assessment is to ask some questions that help the providers establish that their programs do not isolate people.

And I looked at the New York, had developed some questions around this. I'll read them off. The standard is the home is not isolated from the community and does not have the effect of isolating individuals, and you ask questions like, do the residents have the ability to interact with their neighbors, do they... where's the place located? Is it amongst other residential properties? Is it the residents, the people who live there, have access to all the community services and facilities that everybody else has? Is there sufficient transportation so people can get where they need to go? There's a bunch of questions like that, which would help a provider to establish that even though it looks like their facility is in fact, does it isolating individuals based on its physical location. It does freak me out me out because of all (inaudible).

If it's okay, what I'd like to do is add this to the discussion for future meetings because I think when we get to those questions, there's going to be a lot of discussion and I think we're going to need to set some time aside for that.

Okay.

If nobody disagrees, I'd like to add that to the list and mark it as settings that isolate, assessment questions.

This is Melinda South. In that, did they give a definition of isolation?

No, it's really to do with what they call qualities of an institution. Does this place have the qualities of an institution? And there are certain factors that trigger suspicion, such as, they're owned by the same facility, they're owned by the same provider, and they're all right next to each other. That would be, that would kind of trigger some scrutiny, but I mean the response to that would be that you would establish based on your programmatic stuff that that's not the case, that they may be contiguous but they don't - the people are not isolated.

I think there may be, and DDDS answered this question, I think there's probably going to be

different approach for existing facilities than for future facilities. I think that their policies probably to be developed that will make sure that sites are diverse and dispersed and not overly concentrated in one particular spot. But I can speak with DDDS. I just know, it's a policy that they are going to have to develop.

This is Fran. We are again going through the same process internally. But in terms of the work for this committee, I would again just to support some decisions that were made early on to consider programs that are already functioning in terms of maybe having to have some other things happen, some other allowances made versus new programs, new settings that open, so I don't think, I can speak with Jane but as of today, I don't think our expectation is that programs are going to change immensely over the next year, maybe over time, but may be new programs starting are going to be the ones that are going to be meeting these requirements most closely.

This is Libby. So this questionnaire is for only existing living arrangements.

Currently the assessment that you are doing is for, I'm sorry, this is Fran. The assessment is for the current providers, but changes that CMS has imposed or is requiring will be something that all new programs will have to meet moving forward.

This is Terry. I have a question that occurred to me while I was going through some of this material. Does DDDS and the CMS expect that these assessments will be done more than once, or is this kind of a one and done?

This is Fran. CMS expectation is that we have a process in place to assess the programs as they are. It's up to the state to make decisions about how often assessments gets done and what kind of look back there is, and again CMS has not given DDDS any feedback or the state of Delaware feedback on their particular transition plan yet, but I think at some point in a self-assessment process, we know there has to be a look back. We also know that DDDS staff, my staff, will be doing a 100% check within the following year to see if everyone is in compliance with whatever changes they said they would make, but I think that's how DDDS has decided to move ahead. CMS has not been specific about that.

This is Victor. I also just want to comment on what Linda brought up about whether there is specificity definition about the word isolation. Laura said that there really isn't at this point and as I was reviewing the different assessments from the three states as part of our assignment, that kept coming back to me over and over again, but when I look at these kind of assessments, I look at specificity and subjectivity. Specificity almost always gets subject to the almost always path. And when a question like, does your facility isolate, I think a hundred people could answer that 100 different ways, which is why I feel questions like that really don't have a place in what we are putting together here, whereas the follow-up questions in support of whether they do or don't isolate, have all the value, like talking about your transportation, for example. So I just think that as we move forward that we think about specificity versus subjectivity as often as possible.

Everything going through those two strainers, if you will. And to do what we can perhaps, something like a very important concept of isolation, maybe that's almost just like a chapter heading rather than a question asking specifically, does your facility isolate. Instead of under the heading of isolation, then have more specific questions which, if you add them up, you would clearly see or hopefully clearly see that this does or does not isolate.

This is Libby. I agree with what you said and I think when we get to those questions were going to need some time to pull this together, which is why I put it up on the list. So we are going to dedicate some time to that at one of our future meetings.

This is Terry. The only thing I notice in going through some of the state assessments is some of them choose to go far beyond what the CMS regulations appear to require, and I would just advise

all of us to be cautious and selective about adopting some of those more arbitrary or for my perspective, and restrictive types of interpretations.

Okay. So the last action item is closed. Bill confirmed. I sent him a couple emails now and he has responded that he has received them, so we are in good shape.

This is Bill. We will go on to discuss process of tracking questions to possibly include in the Delaware assessment.

Okay. That's what I brought up earlier. That's this list here. Questions possibly include in the Delaware assessment. As we go through each document, we'll include the state, page and the number and any other relevant information. So the first one we are going to go through is South Dakota, and we started this one last week but didn't make it very far. And what we are going to try to focus on today is if the majority of us like a question, Tim's going to make a note of it. If we have some discussion around a question and it's something that we need to further discuss, we're not going to spend a whole lot of time discussing some of these today. We'll add to the list.

Can you hold it up? I have a dozen assessments at this point.

Yeah, and they don't always have their state name at the top. It's the one that we had the number last week with the circles in the bottom. So we are on South Dakota, and we're going to go through, and if we agree that it sounds like a pretty good question, it doesn't mean that it's necessarily going to be typed up in the Delaware assessment. We're just going to take a look at this list. At a future meeting. And then make a decision on which questions will include and which questions we need to create.

This is Victor. Do we have any spare copies? I am looking at it online, which I'm happy to do.

There were some copies last week, I don't know if they're still around or not.

Libby, this is Tim (hear shuffling around papers)

And what page are we on?

Two.

Libby, I have a question.

Yes.

This is Kathy. Once we get our list of questions, do you think it will be possible for somebody to be able to crosswalk those questions to the federal document so we can make sure we're pulling everything in?

Yes. That's a good question. I thought about that, and I'll take care of typing all this up and I'll try to group them together cross-reference them back to the CMS questions document, and I think at some point we'll need to go back to that document again as well. So as we go through these questions, if people say like it, it's okay, mark it, Tim will break it up on the board. If you're not sure about it, just say so and let's just try to keep this moving. I think we have 15 or 20 minutes per state. So number one: number of individuals served at the facility. Nobody jumps up. Anybody? Number two: what living options are offered to individuals in your setting? Check all that apply. At last week we talked about this a little bit, some of the settings for Delaware will be a little bit different, but in general, what living options are offered to individuals in your setting?

This is Tim. I think we talked about adding shared living and CLA's to that?

Yes, supported living. Shared living.

Might be Delaware specific?

Yes.

This is Terry. You might want to make the supervised apartment and SLA, is that correct?

Supported living.

Supported living?

Um hm.

Thant's different, isn't it?

Supported living wouldn't have agency involvement necessarily.

OK

As we continue, I believe the people with the blue tents are the people who are officially on the committee, is that true?

Correct.

So if you have a blue tent, speak up. Whether or not you agree or disagree or you are okay to mark it or not mark it. Bill, you're okay with this?

Okay.

Kimberly, I don't know if you have a blue tent or not. Does Kimberly have a blue tent? I don't know.

You there Kimberly?

Is she a voting member?

I'm here, but I don't have a blue tent. I'm not a member of the public, but I'm not a voting member of the group.

Okay. You're a gray area. You have a great tent. All right. We already talked about the fact that we are going to have a meeting about what our answers, our responses are going to include. So let's not talk about the yes, no because it's going to be more than yes or no for these next questions. Let's just kind of focus on the questions, so number three: is the setting also a nursing facility.

No.

I agree. We are not going to assess nursing facilities.

Okay.

No, no, no. This is to establish whether it is one of these settings that is never considered a home and community based service. That's a question you have to ask.

Along with, are you adjacent to an institution, I mean those are two questions that are geared to find out where your setting is, like if you're on the –

Right.

If you're going to include, I would, this is Terry, I would suggest licensed nursing facility because a lot of homes, some at least, have nurses and I think it gets confusing in the absence of specifying licensed.

Is that a problem, an issue? Have nurses at places that aren't licensed?

It shouldn't be and that's why we'll want to make a distinction.

The regs in a nursing facility, you want to track those, right?

I don't know.

This is Melinda. I think the one thing that Terry was pointing to is we have homes that support people who are medically fragile. Where does that fall in? We have people who do have certified or licensed nurses on, so maybe that's just a larger question.

Yeah, I don't think there's anything sacred about what the feds did, so –

Well except for we don't, the questionnaire doesn't capture the material –

Granted, we have to address, yeah. Their intent.

This is Tim. I'm getting confused on what I need to put on here. (Laughter) should I put up licensed nursing home or – not?

Maybe we leave it up there because we are going to come back to these and look at the wording anyway. It's something we need to address so –

This is Gary. Need a good definition I guess from Delaware.



Okay, so we are including number three. Number four: is the setting on the grounds of our adjacent to an institution? I guess we need to include that question as well. Number four. Is that correct? Is the setting located amongst private residences and or retail businesses? Nobody else is going to speak up. I'm going to say that I do not like that question because it's too general.

That was my thought.

I think we need to come up with a question similar to this, and I think other states have done a better job.

This is Laura. This language is tracking the CMS guidance on the subject of isolation, it's actual verbatim. But you can phrase it another way. That's where the language came from.

Well, it's all from that. But it has to make sense, and we need to drill down for our state, I mean, private residence, is it amongst so, within a mile of, or 10 miles of –

Totally ambiguous.

Yeah.

This is Tim. Why don't I put a checkmark and say reword. Is that okay?

Yeah.

Do you want to, This is Gary, throw a definition in there of what that means.

Can we just say define or something like that?

This is Bill. Can you not speak the antonyms? Can you like say what a CLA is or something like that and bring it down to –

Bill, sorry, this is Tim. Yeah, we'll try and –

And the other people –

Bill, this is Tim. CLA is a supervised apartment. That's what my son is in, so I know this term well. Thank you.

This is Fran. Also, as we are looking at assessments, I want to call to your attention that a question like this is also a poor question because it's actually asking two questions. Unless of course you are residence or a retail business. This actually is two questions.

Yeah, that's a good point.

Right, and some, I read in at least one other document from another state, this question was drilled down a little bit further, so I think rewording and redefining is good. Is there another group homes supervised apartment, monitored apartment or assisted living center on the same block? And I guess that's the kind of question that goes into our settings that isolated the discussion. So I would say that we don't want to include that question at this time until we have time to discuss it further. Or we have to handle it like five, I don't know.

Well, these are questions for this list. These are no-brainer questions. We all like um. It's one of those, yes we are going to include a question like that. But the ones that we need to discuss, we know that we need to address all these topics, but we need to have a discussion on several of these before they go in the questionnaire. So what I was hoping is that we make a list of topics that we need to discuss further and then the questions that are no-brainers that's included pretty much as is –

This is Gary. I was just wanting to point out where five is ambiguous, six actually gets a little closer to being discreet because it says the same block. I mean it's a little better defined but still it's like then, how you define other things. I mean do we know what the supervised apartment is. Is that a CLA? Clearly monitored apartment? Is that something we, that's why I always, don't know enough about that question to say keep it or toss it. That's what I need help to understand why it wouldn't be included I guess.

It will be included, just not on this list that we are putting up here. It is included on that list that we

are going to discuss this whole topic at another meeting, and after we discuss it as a group at another meeting, then from there hopefully we'll be able to agree on the specific questions for the assessment. If this doesn't work –

State of Pennsylvania or some different state –

I mean if this doesn't work we can do whatever we want to do, but –

Sounds good.

So if it's not on this list, it doesn't mean we are throwing it out, it just means that we have to go back and talk about it more.

Okay.

This is Victor. This is coming directly from CMS I assume, so that is the key rather than being a certain radius around -

Different data collection? Doesn't mean that they are not going to be considered only in a community setting, but it's case information that DDDS would need.

This is Fran. I might make a suggestion to keep in mind that we are going to looking at many more assessments and maybe part of what we also want to see is whether or not we like the way the question was asked, because we also need to collect that information. So we may have a hodgepodge of multiple assessments.

Next page, number 7. Do Medicaid HCBS individuals receive services in a different area of the setting separate from individuals not receiving Medicaid HCBS?

This is Tim. I'm really, I'm having trouble understanding this question. I went over this several times at home and I just don't quite get it. I was thinking that if I personalize it, does my son receive settings in his supervised apartment receive services in his supervised apartment that are not residential services like PT or OT\* or something like that.

This is Gary. When I read that, I am thinking they are trying to determine maybe inclusion or something that it's being handled in the same area, not being excluded and being handled somewhere else, I don't know, that is just my -

This is Fran. This might be a situation where an example might be if there is a housing complex that many people live in and there is access to say a pool or a recreation area, individuals with disability would have to enter through a separate door.

This is Terry. There are so many interpretations of this, I think it's a poor question. I think we should move on.

Number 8. Does the setting isolate? That doesn't mean we're not going to address that issue. We will just come back to that. Does the setting isolate individuals from the broader community? I think that is very vague and I think other states drill down on that one.

Yes. Skip it.

This is Tim. I think it's clear as a bell.

It can be answered in a million different ways.

Does the setting isolate, in other words, where my son lives, I personalize it. Does that isolate him from getting into the broader community. I think that's pretty clear. In my son's case, not at all.

This is Bill. I agree with Tim.

I think it's just so vague it's useless, isolated is a totally subjective term.

Although it can be defined and we can agree on the definition. Whatever it may mean. I think it is worth at least discussing. The list that you had a future discussion in.

Yeah. That was Gary. This is Libby. In one or two of the other states that actually has examples such as going to religious services or going to the store, so

Those are meaningful questions. This question is too vague.

If it's left the way it is, yeah. We have to -

So we are going to address that question, but. Does the setting restrict visitors? Personally, I like the questions that ask a positive question. Is the setting open to visitors, and I think it was turned around that way in a couple of the other states as well.

I think that sounds better.

This is Tim. Can I put it up and reword? Like we did the other one?

Sure.

Does the setting restrict visiting hours to specific hours of the day? Okay, so maybe this process isn't working. I'm open for suggestions.

It's kind of slow, you mean?

No. I think we are going to have a list of all the numbers up there. Basically that says, most of them, just reword it. So do we continue down this road or make a change while we can.

This is Tim. I think Libby this is actually, I think where we'll, I like the fact that we've got things up here. We've discarded some and we're rewording others. And as we go through the other states, we'll get some of that wording too.

Okay.

I was trying to think of how this all could go if we didn't do it this way. And I think it would end up being a hodgepodge of people just bringing in their own questions and I think it would be more difficult than this process. I know it's slow, but -

This is Terry. My suggestion would be let's vote on which of these assessments we like best and start with the ones we like best and perhaps in going through the first couple that we like best, we'll have 80% of our questions identified.

I'm sorry, this is Gary. When you say assessment, you are talking about this whole document versus this document from another state, or are you talking about the items?

The assessment document.

That includes all items.

Yeah.

This is Tim. The only problem with that and I don't think it's a bad idea at all, is that I doubt if anybody around the table has had a long look at Connecticut, which we got very late this morning, which to me looked very good. Maybe that could be another assignment for next week. To make sure we go through all of what we've got and then we could go Terry's direction.

Right. And if we say that what we have is what we are going to work with at this point, we might miss another one that comes in two weeks from now that might be better, but there's not a location for all of these out on a website somewhere. States are still working on them so we are getting them

as people find out about them.

This is Gary. Do you want to make that a homework assignment? Or an agenda item for next time, for homework, to go through these and choose one that seems to reflect what we in Delaware are trying to develop, and maybe we can then identify questions from others that you can plunk down in this somewhere. If you understand what I mean. If Connecticut looks great, looks better than the others, for example, there's a couple of things in here that could be moved over. I am trying to -

I just thought, Mike and this is one of the poorer lists in terms of effectively utilizing our time -

I think Pennsylvania's is a scary assessment. Pennsylvania has way too many policies and proofs of this. Pennsylvania has -

How many do we have at this point, maybe six?

You've got the two, South Dakota, Tennessee, Pennsylvania, Connecticut, Hawaii, we've got five. Plus the CMS. The CMS, the questions.

This is Tim. I think we can easily work from the five. If we keep getting more states in, it will kill us, and we've got to get this thing done by June 15th.

They're all the same but worded differently.

This is Gary. If we could figure out the essence of why they ask that question that came out maybe ambiguous, but there was something they were trying to arrive at, maybe we can specify that. If we can figure it out. If you understand what I mean. (phone ringing) So it's clear to everyone. (phone ringing)

This is Tim. I would suggest that we at least enter South Dakota so we have a sense from one whole state's document and that is going to take quite a while I would guess, and then we can have as a homework assignment to look at the others and decide which one we want to take a look at next.

Okay, this is Libby. Another option that I tried to do, and I think a lot of these came through as Word documents, is just mix them up, similar questions together so that we have a document that mixes all the questions together. Kind of categories. They're all very--

A lot of work.

Yeah, but you know what

Break this group into little work groups to work on the one?

I mean going from document to document and having all these documents all over the place trying to say okay, which question do we like best, that is another option. Let's continue to go through South Dakota and -

This is Terry. Libby, for whatever it's worth I think your idea would work well. It's an incredible amount of work, but if you don't mind (someone chuckling)

This is like a term project almost. Answer these questions and then group them together.

I can certainly understand if you don't want to do it, put it that way.

I don't want to continue to waste time trying to go through these when we are. The question is similar to this state and it's federal on this one and, without having all of them open at the same time.

This is Kathy. One of the things we are going to run into with five different documents, we are going to forget which one of the ones we liked versus the ones we said we didn't like. As we keep going through and as we split everybody up into the smaller groups, are going to start having that problem too. Well, we like the, well, was that Connecticut or was that -

This is Gary. Unless you would, initial the state at the end of the question or something like that I guess. I don't know if that solves what you are thinking.

This is Victor. Since we have 5 or 6 altogether at this point, that seems to be pretty manageable to me. I agree with Tim that if we just keep it open ended by as we approach the beginning of June, we could have a dozen that we're reviewing, but I like the idea of being able to visit each one of the five or six more closely, like between now and next week, and I feel from looking at them up 'til now is that some of them by and large are far more specific than others. Some of them may go a bit beyond what CMS says is required. If we just start mixing and matching all of them I think that could muddy the waters as much as clarify things. And then if we all come to a consensus that this one or these two are clearly better than the others, maybe we can focus on those and add and subtract as we feel is necessary.

This is Gary. We have two approaches. We have tearing each of them apart and clumping them together in similar categories or questions. Or choosing one state's questionnaire and adding to that or subtracting from it, is that kind of, I'm hearing what you are saying and then what Terry was saying was looking at one particular state, is that Terry, what you were considering?

I think we've talked about different things, but one way would be to identify which ones we like best and perhaps use that as a starting point, but Libby also brought up the possibility of looking at all the questions that ask about visitors, for example in deciding which one or two we like best. From my perspective that makes sense, but on the other hand I recognize it's an incredible amount of work, so I'm not sure what's the best way.

This is Libby. Why don't we continue down the road that we started here with South Dakota and I'd like to take a stab at trying to merge these documents, similar questions together. And if I start it and it's not making any sense or I can't, if the questions don't appear to group nicely, then I'll let you know and we'll figure out where to go from there. But like Terry said, everybody has a question on keys and doors and furniture and visitors and all that, and those are pretty easy to group. So I'll try it.

Thank you.

This is Fran. Just as a suggestion, the CQL document that Terry handed out today may be a good template to use for that. To be able to just put it in boxes and then -

Okay.

And Libby, if you'd give me a section I'd be more than willing to go through and take that.

Okay.

And see, so if you want to look through it and assign me a couple, I'll look through the document and group them together.

Cool. Good. Thanks. So let's keep going on South Dakota. Did we cover 10?

I think it's a variation of 9, isn't it?

Visiting hours?

Yeah.

Do we have a policy that restricts hours or we don't? Can't you answer that question yes or no, what's the problem with that question? This is Laura.

I think it depends on the people that are in that.

Can you write that in? Can you explain that? If you restrict hours, then you are not supposed to restrict visitors, the standard is we don't restrict visitors. If we do restrict visitors we are going to tell you why we do it. Right?

It is unambiguous. For whatever that is worth, yeah.

Um hm.

So then if you are trying to ascertain whether they have a policy on visitors, this would be a good question.

Um hm.

Unless you say do you have a policy on visitors.

Or what's your policy on visitation.

When do you restrict visitors? Why do you restrict visitors? This data needs to be obtained.

Right.

This is Terry. If the answer is no, I assume the assessment can move on. If it's yes, you are going to have to explain yourself.

Right.

It's a fairly good question.

Next, physical accessibility. Are there any physical barriers that individuals are not able to open, move around without staff assistance? Similar to number 2, are there obstructions that limit individuals' mobility?

Sounds clear. This is Gary.

This is Tim. Do you want me to put it on the board?

That is what we are saying, yes.

This is Bill. In question 1, again like Terry said, if they answer question 1, no, then they can skip 2. If they answer question 1, yes, then they have to go to question 2.

Well one has the staff assistant item on there. The other one doesn't.

One's about barriers and one's about obstructions. They're different. Something might limit your ability and the barrier prevents you from, so they're conceptually -

Yeah, I'll go with that.

Is that understandable, Bill?

Yeah.

Are appliances accessible. Yes, everyone, no anyone. Yes, speak up, guys. Is furniture placed to allow individuals to use furniture independently? Left side of the room.

I would say yes.

Good.

This is Victor. Can we go back to number 2, where it says something as simple as are appliances accessible to individuals. That is where we are going to have problems because it should say something like, are accessible to all individuals, because it could be, you could consider it to be accessible to 80% of the people there and clearly not to some other people there.

So for that one why don't we put a note. Just all individuals so we don't forget about that. Number 3.

3.

And I think we're on number 5. Has residence been modified to meet the needs of all individuals? Number 5. Laura, Bill, Gary, Victor. Okay, number 6, does the setting have stairs or steps. Bill, this is one of the ones, if you say yes or no, then you have further questions. Are all individuals able to use stairs without assistance. Is there a wheelchair lift. Are there railings in stairwells, steps, ramps?

This is Fran. For the question about wheelchair lifts, I would suggest that if we use the question, may want to insert working wheelchair lifts because we often find that there is wheelchair chair lifts but they're not working.

(inaudible) is a good point. Functional is a good word.

So we're going to keep number 6 and the subsequent questions? So, Kyle is joining us and we're on South Dakota document. Page 5. Number 1. Do individuals control his/her personal resources?

This is Terry. I think it's too vague but can I assume we have to have some version of it, so maybe revise, we've got other questions.

This is Kathy. We had some discussion on this at the last meeting and I think you said to add personal possessions. I have personal resources and personal possessions.

I think if you had funds and possessions, you've probably got a fairly good question.

And I think that might have been where we landed last week. Personal funds and possessions.

This is Gary. I remember that was a guardianship question. I think it triggered in my mind, there was some issue regarding that.

Right. Are individuals allowed to decorate their own living, sleeping areas? Is that a yes or a no or maybe?

Yes.

Do individuals in residential settings have a lease agreement or formal written agreement with the agency that covers termination of a lease, eviction, etc. Yes?

Yes.

Do people who are -

This is Tim. I'm really not quite sure what they're after in this question. Do individuals in residential settings have a lease agreement? This make you think of the Ark homes, Terry?

Yeah, I think or formal written agreement is the key qualifier there, and this is Terry. From my perspective, I think a solution, I'm not it's necessarily the best, would be for DDS interested parties or others to come up with some sort of standardized proposed agreement and if a provider chooses to use something else, they would have to get subject to approval, but I think the simpler

and more straightforward it is, and if it is happen to be standardized, the better, because otherwise it's going to be all over the board.

Well the way, this is Tim again, the way I read this made me think that the agreement's got to be between the owner, in other words, you, the Ark, and the individual. I know the Ark doesn't want to do that.

That is not the case for any of our houses.

But the way it reads -

Right, I agree with what you are saying.

But Tim, I think the provider has more control over who resides there than we do.

I understand, Terry, all that. This is Tim again. But this wording makes me think of a landlord. I wonder if there's a way we could reword this to get away from that.

I think if we do an R by this, and then Libby has our list of questions, we should be able to drill down which version we like best. Does that make sense?

This is Tim. Can I put up 3 and reword?

Yeah.

I was just going to address his question about whether the lease has to be between the immediate owner of the property and the resident. It doesn't.

The reg says the unit or dwelling is the specific physical place, which could be a room, that can be owned, rented or occupied ... the agreement is not between the resident and the owner. So it's owned, rented or occupied under legally enforceable agreement by the individual receiving services and this individual has the same responsibilities and protections of eviction that tenants have under the landlord tenant law of the state. So its supposed to replicate the relationship, there is more, so that there's more of an arm's length relationship, I guess, and it has some of the protections in terms of termination that tenants do in the private market. My question about this is how does that dovetail with the fact that long term residence protection has discharge proceedings that protect people from being discharged. I haven't quite figured out in my mind how, but it's an interesting idea. But some sort of more formalized document has to be produced like, Tim was -

Terry

Too many guys. The same. There's got to be something. Doesn't necessarily have to be a lease, but has to be some sort of written document. Must be enforceable. So it's an interesting -

Legally enforceable is going to be challenging I think.

Yeah.

Okay, so we are going to add that with a reword.

Yeah.

Okay, and that was Laura who was speaking previously?

Yes.

And you were reading through the CMS document? Is that correct?

Yeah, that regulation.



Number 4, do people who are not HCBS participants or staff live in the setting?

I would say yes for foster care or shared living, who would want to keep that in there, correct?

This is Terry. Setting again is a very ambiguous term. Are you talking about the unit or are you talking about the complex, are you talking about the development, are you talking about the neighborhood, I assume it's probably something close to building, but I would say reword.

This is Gary. It sounds like, one you have to wonder, okay, what are they after with that question since it's -

This is Kyle. Didn't we talk last week about possibly having a set of definitions?

Yeah.

Setting is used a lot, so that would be something that maybe we could define.

Parking lot?

Yeah.

This is Victor. Isn't it possible the way that this is phrased currently is that sometimes the same provider could answer it yes and sometimes answer it no, given on whether this kind of person that they are asking about is currently living there, so are they interested more in, is our, do people who are not HCBS participants or HCBS staff live in the setting or is it more that they may live there, are eligible to live there because any given time, there could or could not be potentially somebody in there, and that would affect the answer to the question.

This is Laura. What I, this is one of those isolation questions because the next one is also and has to do whether the setting which is where the persons living who are getting the home and community based services funded by Medicaid program, do they, is that environment integrated with individuals who are not waiver participants, like in an apartment or group home, is the next door neighbor, I think it's getting at that integration part. The next question also is addressing that. So, that's what we're getting at. It's not a very good question, I agree with that. It's kind of awkward.

But are they interested in do people or are they interested in may people who are not HCBS participants etc.

This is Terry. I suggest we move on. I think we're spinning our wheels here.

4 and 5. So 5 is the same?

Well that is a pretty straightforward question. Is it physically identified as a residence for people who are either elderly or disabled.

This is Terry. I can walk into a home and tell you whether it's specifically designed for persons with disabilities, but that doesn't mean it has a sign in front of it that says, home for persons with disability.

I think what they're saying is HCBS doesn't want these places to have signs on the front.

Right.

(People talking over one another)

I wouldn't read that at all, but -

If that is the issue, then the question is -

Is that what the fed's register says?

Is there a sign in front of the building.

Yeah, I mean what's wrong with asking question, is there a sign or not.

Is that what the register -

Right. I think that would be far more clear.

What the guidance says.

Yeah.

Okay, I am sorry.

I think that first circle there, is there a sign in front of the setting, I think that makes sense.

Right.

It just goes back to being more specific.

Right. I have no idea what they're going for, but that's what it says. Could we get copies of the federal registry?

It's online.

Okay. CBS or?

Federal register, you can get the regulations and all the comments which go on for -

Yeah, I don't want the whole comments and crap.

This is Victor. Laura, is it just about the sign outside the place or any way in which it is promoted?

What they're looking at is evidence one way or the other whether this particular residence blends in with, is part of the community or not. And if it's got a big sign that says, this is a home for people who have developmental disabilities, that is not blended. If it doesn't have the sign, then it's more blended than it was before.

It may or may not be.

Right. It may not be blended, but at least you haven't labeled the residence so that everybody can see and knows the living there. I think it's just evidence one way or the other.

Okay, so number 5 is --

It's the old Wolfensburg normalization criteria. I mean this goes back decades --

It's been around a long time.

Number 5, reword, let's just move on. And the next one we talked a lot about the last go-around, some of these didn't apply. Are there areas in the setting that are restricted to individuals that have not gone through due process?

This is Kathy. I think at the last meeting we said to take off the, that have not gone through due process part. I have a note to that effect.

Because it's not really a procedure that the Delaware, I think it must be something specific to South Dakota.

Do we need it at all?

This is Terry. It's a rights issue. If portions of the home are restricted in the sense that a consumer can't go there, then you have a restriction. The due process relates to some formal decision making

process that justifies that portion of the home being restricted, so it's a context issue, but I do think it makes some sense.

Okay, so we are going to include some version of this question. Number 7, do individuals choose when, what are where to eat? And again I think we need to include this question but maybe reword it better in another one. So we'll take a look at that. Bill, did you have a question?

Yeah, he wasn't understanding -

I wasn't understanding the due process.

Okay.

You are allowed to ask if you don't understand something.

This is Kyle. Did you have any question on that or -

Did you get your answer, Bill?

Yes.

Okay, number 8. Are requests for services and supports accommodated? I believe last week we said services and supports need to be defined.

Yes.

So I don't think we need to put that one up there. Is information about how to file a complaint grievance posted in obvious location and understandable format?

Yeah.

Yes. Bill, you have to actually verbalize your yes's.

Yes, Bill.

Thank you. Can individuals make an anonymous complaint?

Yes.

Yeah, that is right.

This is Bill.

Okay, privacy. Can individuals lock their bedroom doors when they choose?

Yes.

Yes.

If you don't speak up and say no, then we are going to regard it as a yes.

Do individuals have privacy to perform personal hygiene?

Yes.

Are there cameras present in the facility, and this is Libby. I know that several of the other assessments had more verbiage around this that was pretty good, so I would say yes with reword.

Yes.

Can individuals consult with their health care provider privately?

Yes.

Yeah.

Do individuals have access to telephones, TV, radio, internet, other devices in an area that affords them privacy?

Yes.

Yes.

Does staff only use a key to enter a living area or privacy space under limited circumstances agreed upon with the individuals?

Reword that one.

Number 6, reword.

7, do individuals have a key to the setting?

Yes.

The other side of the room want to speak up. Laura, Bill.

Yes.

Does the setting have a location where individuals can visit privately with guests?

Yes.

Yes.

Is information about PT, OT\*, meds, diet, etc. posted where non-staff can see it?

That is a good one.

I like that but I would rather say a positive one on that. Is it only visible to appropriate staff or something like that.

We can reword.

Reword. 10. Do individuals share bedrooms? If yes, do individuals select who their roommate is.

That is a good one.

Yes.

Dignity, respect. Number 1, are restraints utilized in your setting?

Oh, yeah.

Yes.

Okay.

I am not familiar with all of that. Kind of like, but that is probably outside of this meeting.

You don't keep it in restraints.

Well end restraints.

Again is one of those words, what are we talking about. Restrained access to things, it's a whole rights thing that we have to go through when we look at our human rights committee stuff.

So maybe restraints can be defined a little bit, or examples or something. That was number 1.

Number 2, page 9, do staff talk to others about individuals as if the individual is not present or within earshot of others in the setting? How do you prove that or how is that related.

You have a policy that addresses that, right? Of course you are going to say, no.

This is Kyle. Who is going to actually answer that, if it is occurring.

It sounds more like a licensing standard.

Or privacy protocols in place.

This is Fran. My guess it's speaking to privacy and law of confidentiality.

Kind of need a little rewording.

About respect.

Number 2, reword.

Yeah.

3 has -

Respect area, it's, to me it's not just policy but it's also training.

Could you include that, policy and training? With reword? Do staff address individuals in a manner in which the person would like to be addressed and is respectful to the individual?

Yes.

Yes.

And would that -

To me that sounds like that question is being asked to the wrong people. I just think that every provider's answer gets to that. It's more important (inaudible).

This is Kyle. I agree (inaudible).

My guess is that you are not being recorded, Kyle, and Victor. If you guys could speak up a little bit.

This is Victor. I was saying I believe that question is being asked to the wrong people because the value of the answer there comes from the person on the receiving end, how they believe it is or is not being done rather than through the provider.

This is Libby. Does that go back to the policies and training, kind of?

How would shared living providers prove this?

Yeah, I (inaudible) policy training piece.

This is Fran. A suggestion may be to consider, there may be some of these questions and part of the assessment may be that the person doing the assessment has to go back and ask somebody for their response to some of these so they can get accurate information.

Libby, this is Victor again, and I think probably the answer is yes to your question, is this more of a policy and training issue. Because if you are asking the individual, I think you can ask that question directly to them here. I think the only value of something like this being asked of the provider is, do they have policy and do they have training in this area.

This is Tim. This brings up the issue that Libby mentioned earlier of having, do we want to have an assessment by the individuals, him or herself. Because I have seen this question redone in those assessments, so that might be a thought for the future. If we want to do that, then we can build this question right into that so the individual can complete.

We want to write on that one behind you, Tim. Maybe South Dakota page 9. Numbers 2 and 3 as

examples.

Possible consumer assessment?

Yes. When we talk about that later. Okay, number 4, do individuals ever have to earn the right to go out in the community?

I think that could be better stated.

And same with 5, have the right.

Yeah, that is a whole, but I understand -

The idea behind it.

I'd like that to be recorded. I don't think it's ambiguous at all.

No, it just, yeah, I just don't like the way it's worded.

I'm looking at the word, earned. Sort of, what does that mean?

Earn the right.

Part of a behavior plan?

Right.

In order, if you want to -

Yeah.

You have to say, you have to -

So if you want to operationally define this, as they say, you would have to be a little more specific, with an example.

This is Terry, and I guess one of the things conceptually we need to be thinking about is how are these various issues relating to individuals going to be verified, and from my perspective, the simplest answer, and I am not saying it's easy, but it gets back to what I would call the ELP or person-centered plan, so on and so forth, and basically I think somewhere in the person-centered planning process, there should be what restrictions are placed on this person and there maybe should be a list of 20, 30 probes. And any restrictions that exist, the team should have the include why that is the case and some of those types of probes are included in that document I emailed to you guys today. But I think one of the things in talking with my colleague Suzanna from the day program thing, they've already agreed that a lot of this documentation, that makes the most sense, that it should be in the ELP, and the more you have one inclusive document that is summarizing those kinds of issues, the simpler and more measurable this whole process becomes for everybody, so I think conceptually it's an important issue.

So this is Libby. I'm barely familiar with the ELP's. But they certainly don't cover everything that is included in here, is that correct or does it touch on most of these types of things, like do you have a key and --

This is Terry. I think if you are just focusing on the individual pieces that are specific to an individual consumer, you come up with a better idea of those kinds of issues that could perhaps most efficiently be addressed on some sort of ELP protocol, outline, whatever you want to call it.

This is Fran. I would just caution that the ELP is written by the state case manager, so if this is a self assessment for the agency, there may be some conflict with the state case manager writing -

And this is Lisa. No, this is not included in the ELP's that they have their own keys. Like Fran says, it depends on the state case manager, but no. And some of these questions are scary, that you would have to earn your right to go in the community. The thought that people are even asking this makes me cringe.

Yeah.

But some people need supervision in the community, so it becomes a matter of -

You have to earn your right to use your own possession?

Yeah, it's objectionable from my perspective too.

Okay, Bill did you want to contribute something?

Yeah, but even if they do have supervisions, they do have the resources to go get them.

That is a good point, Bill, it's Melinda South, sorry. That sometimes we say do people have or earn the right to go out and do these things but they might not have the means, so that can also be a restriction as well. We might all want to go out and do certain things but we might have limitations in order to do that.

This is Libby. So when we're talking about person-centered plans, and I mentioned before, my daughter is 22, and this residential world is fairly new to me, and I am learning quite a bit. There really isn't a person-centered plan right now. Is that -

This is Fran. The person-centered plan is a combination of the ESP and the ISP, so, I'm sorry, the ELP is the plan that the individual and supports, I'm sorry -

Can you spell it out for Bill?

(People talking over one another)

Essential lifestyle plan is done with the individual support and significant others and natural supports and describes what that individual, the choices they would make for their life, and then the individual support plan or some of the other things that we've been discussing off and on, such as do there need to be restrictions on the kinds of food someone eats, does there need to be restrictions on availability of going out into the community alone. Is somebody able to go down to the store by themselves, what if they need to go to the mall, they need somebody else to help them. So that is the initial support plan that talks more about the kinds of things that may be more safety issue related.

Who participates in that process, Laura?

Everyone should participate in that process as well. But I think that ISP process is more, when we are saying ELP, I think those two processes get mixed up, so the essential lifestyle plan is, I'd like to go to church every Sunday and to be able to get there, but the individual support plan may be that I want to drive there myself but I don't have a license. So I need help to get there.

So just one clarification question. The ELP is not residential specific. Is the ISP for people in residential placements or is that -

Yes. A family support specialist, you can still have an ELP. Definitely a person centered plan is for everyone. ISP is the kinds of supports that you would need to have in order to be successful to meet your goals.

For example, one of the things that this covers is like, the key issue for example, if you have

somebody, the general standard is that people have keys, but there may be individuals who should not or who may not have the keys for various reasons. That would be documented in the ISP?

Yeah, so in the ELP, I want to have my own key because to me it says that I have my own place to live. But I have an issue with Pica and I swallow the keys, so in the ISP, I have a key that someone holds for me, and when we get to the door, I hand that person the key and they get to open the door themselves and then give the key back to me.

So part of this process, we need to do the documentation issue, there's a deviation from the – Yes, so that particular facility would have to say yes, everybody has their own keys, but one individual does not hold their own key because.

Okay.

And they would have to describe then what they do instead.

Is there that level of detail in that process?

Absolutely not. It's just an example to kind of make it concrete.

In a perfect world, Fran should write the ELP, but I have many people that have keys for their houses. It is not documented anywhere because it's a natural occurring event, that it just happens. This is Terry. The thing that should be documented is why those who don't have their keys don't have them.

Yes.

This is Melinda South. I wanted to just point out one thing, too. That is if there are any rights restrictions, they need to be approved by Probus and HR state. So there are committees that approve any rights restrictions.

This is Fran. Probus is, I don't even know,

This is Tim.

Personal rights something.

Just think of human rights committee. It's a group that gets together and reviews all this kind of thing to make sure we're all doing things in the correct manner.

This is Fran. Probus mostly deals with issues that have to do with anything that's out of the ordinary in terms of behavior or mental health.

Psychotropics, restraints and

Psychotropics, a certain level of supports that may be categorized as a restraint.

In residential settings? This is Terry.

But keep in mind again, we're talking providers. These tools are going to be used for foster care.

They don't have the same documentation that we have, so –

Foster care will be doing their own assessment I believe and I can find out for sure.

I thought the assessment –

Foster care is –

Shared living. So they don't have, their ELP's are not as detailed as ours I don't think.

Okay, this is Lisa Green speaking. That was Lisa Green, sorry.

Correct.

This is Tim. A lot of us are beginning to give our names. Number two. As I listed this, I think it might be really helpful for all of us to get a blank copy of what's in the ELP currently. It's my understanding from Jane Gallivan that the ELP is being redone right now. But if we could get an old copy, at least to those of you who haven't seen it, I think it could be helpful to you, especially when you come to think of some of the rewording we want to do in these documents.

I would be happy to do that. This is Fran. Some of these get into the nitty-gritty, but the larger issue around a key, so you wouldn't necessarily be discussing key, it's an access issue. Does everybody



have equal access. And the example might be, yes, everybody has a key.

Thanks for that suggestion, Tim. This is Gary.

This is Libby. Can we get an example of an ISP? And a Probus, and an HRC?

This is Fran. The example of an ISP? Probus is a committee. So what I can do you is bring to you examples of what kinds of things make up a committee.

But the HRC is also a human rights committee, if I'm not mistaken. So Probus is kind of a more specialized unit within human rights or are they totally separate.

Probus interfaces with human rights, but they're separate committees.

I think Probus is more just psychotropic meds, that they have to be approved if they are on psychotropic meds, that they might not have restrictions. HRC is if they have rights restrictions.

This is Kathy. (Inaudible) behavior analysis, just get the paperwork together to a Probus meeting and what you're saying about the psychotropic is in addition to the behavior support plan that behavior analyst wasn't developing for me. So she said she had to take all of that information and have it approved by a Probus committee before she could actually start, and it wasn't so much to restricted as to build in more intimate living skills for him. In addition to this.

This is Melinda South. I just want to say I know the state has a rights policy and may be reviewing the rights policy might be a quicker way of giving, then giving Probus or HRC information, which is explained in the rights policy.

This is Libby. The reason I was asking all this is because during a future meeting, maybe next week, we can talk about it. We're going to talk about documentation, how do we provide proof or evidence, and I was just wondering if these documents or types of documents that people would refer to in there, saying yes for these three people but sometimes for this person and it's based on their ISP.

This is Terry. I think one of the things that might represent a significant option would be something like a human rights assessment. I know I am causing fury among people within the room, so let me explain. There number of things embedded within the federal registry, and I want to add a request here from my stack of stuff on the community settings from CMS is this thick, so if you could send a link to that one, so I don't have to dig through my 2 feet of documents, I'd greatly appreciate it.

Do you want the whole thing?

No, I have the one with 90 pages of comments. I want just the one with –

Just the regulations.

Yeah.

What's the number?

Or where to find it if you have that handy.

Citation.

Well, did you ever do ECFR?

Can you send a link?

I can send it, yes. That would be easier.

Thank you. But getting back to the issue, if we distill down all of the key probes that relate to individual consumers, you could have an assessment where you're identifying where there are restrictions including rationale for it. So I realized that may sound intimidating at first thought but I think it may be worth considering. And I might be able to find something so I will try to find something for the group to consider.

If we could get back to the assessment. Let's try to finish at one today. I know it's not going to happen but let's try – (chuckling)

We were on 4.

Page 9.

Where a number 5, I think.

Tim doesn't have it up there.

This is Tim.

We need to make a –

We were talking about 4, then moved to 5, didn't make a decision about either. I was getting the sense that we didn't like either because of the word earned.

Right.

This is Kyle. But I think it's important that the places are actually doing this, I mean you need to know, and it might need to be reworded because even if you answer no, which would presumably look like a good answer on this, it's may not be because someone could answer know and will have to earn the right to go out in the community. Maybe they'd never go out. (Laughter) so they don't have to earn that right.

Good plan.

I think we need something in there about this, whether we need to reword it.

I suggest we reword both 4 and 5.

I agree.

Number 6, does staff ask individuals about their needs and preferences.

This is Tim. That exact question is in the ELP. Just so you know.

Getting back to basics.

So include –

It is but I think there's even greater value if that were asked in a separate assessment of the individuals.

Or if it was explained or there are examples, needs, preferences –

Number 7, do individuals express satisfaction with services being received?

This is Melinda South, so we do a satisfaction survey for our homes. I guess that would qualify, correct? Sent out to our families and people in support satisfaction surveys?

In this case it would be a consumers I think. This Terry.

This is Lisa. This is something that the DDDS do monthly in their new role. They make either the face-to-face contact or see them at the day program and ask if they're satisfied with the services.

That's part of their oversight rule, correct, Fran?

That's correct, this is Fran, and OQI also does quality service reviews which are very focused surveys on randomly chosen individuals throughout the year to 290, 300 a year and those are questions that are also asked at that time. Again that's the state piece of it though.

I'm sorry, this is Laura. What –

The office of quality improvement does it and the state case managers do it.

Part of their oversight.

This is Libby. This is a question that we don't need to ask the providers?

This is Fran. Melinda would like to elaborate a little bit more on her question, I think what I heard her saying is that if an agency does client satisfaction surveys and they say yes, people do express being satisfied with the services and our evidence is, we do client satisfaction surveys and here's our quarterly results or hears our annual results.

This is Victor. Yes and no seems too complicit because for timeouts, many individuals, so it seems the more value here is to what degree do they express satisfaction and give supporting documentation.

This is Gary.

I'm sorry, this is Melinda South. Then we would need to require all, every agency to do that. It's going to make a lot of work for us.

Is that a requirement in the CMS?

No.

This is Tim again. This is another question we could put in, the persons self-assessment. It's much with their better.

Yeah.

Number 6.

I think we put that one of either, South Dakota, page 9, number 7. Is health information about the individual served kept private.

Yes.

Yes?

Um hm.

Are individuals allowed to keep their own clothing.

This is Bill. Would that be under the envelope?

Privacy. This is Terry. Bill, I think it is there but that might be a question we want to ask anyway. Good question.

This is Bill. But how can they do that if it's under the HIPPA law? How can you provide, how can you say about the health if it's under the HIPPA law?

Nobody should be disclosing personal information. That's what HIPPA requires. But I think it's still worth potentially assessing it here because not everybody complies with HIPPA if I had to guess completely, does that make sense?

This is Fran. There may be some outliers who aren't familiar with-hop, it's something they want to assess for themselves. This is Fran again. Bill, if for no other reason this is a question that prompts agencies to go back and review HIPPA and make sure everybody understands HIPPA and anything that's been updated, and the staff are in full compliance with it.

This is Laura. I think it's beyond HIPPA in terms of disclosures of health information. It's the more subtle stuff like talking in front of other people. It's so easy to fall. Doctors offices started not being very strict about that but now (inaudible). I think that's part of it. I don't release your medical records without a release form. It's also subtle like when other people's families are in the room I'm not going to discuss your information. That's more subtle, it's more difficult to measure. But I think maybe some of those policies like, what's your policy on that.

That would be good to add at this time.

Policy. Should that be a policy kind of item?

Policy and training question. Like the other one.

This is Terry. Having a policy does not necessarily ensure compliance.

I agree with that.

So that's where the training comes in. This is Gary, just commenting.

All right, page 10, number 1, are individuals allowed to choose their own clothing.

This is the self-assessment now, just FYI, this is Terry. Or maybe not. I wondered why it went back to 1.

I think that's a different section.

Sorry, my mistake.

This is under autonomy I guess, which got which is on page before hand

My mistake.

Choose their own clothing, yes?

Yes.

Do individuals control have control over their daily schedules.

Yeah.

Can individuals choose their own hairstyle. Are individuals in the settings aware of how to make a service request. We say that need some rewording.

Reword.

Yeah, this is Kyle, service requests.

For what?

Don't really know.

Number 5. Do individuals know how to make a request for a new provider.

Lets reword that one too.

Community integration. Do individuals shop, attend religious services, schedule appointments, and have lunch with family, friends in the community at any time the individual chooses.

At any time the individual chooses (laughing).

I think it needs reworded.

Yeah, and I think one of the, this is Libby, I think it is almost reworded better in a couple of other states but is, we need that question.

This is Fran. I would also suggest that there's multiple questions here.

Yeah, I was going to say that that is pretty loaded up so okay, if they don't allow religious services to just, it's a no.

This is Terry. By the way, if all four answers are yes, that's only for activities in the community which is pretty restrictive anyway.

Number 2, can individuals come and go at any time.

That's not very restrictive, so that could make up for anything (laughter) that one did not cover.

And then it says if no, check all restrictions that apply. So we are saying we're going to keep that, maybe take a look at that.

There's more things in there on the next page.

Number 3, are individuals aware of or have access to information regarding activities outside of the setting.

That's a good question.

I don't like the way that's phrased. Are they aware of, that could be good enough. This is Victor, or have access to information regarding, it seems that there's a responsibility to the latter part because there's a responsibility to the provider if the first part of that question indicates that if the person is just aware of, that's good enough.

Reword.

Clearly not good enough.

Have to reword that one.

That's a keeper, but reword. Number 4, do individuals have access to activities not coordinated by the facility. Yes?

I think it's good.

Bill?

Yes.

Anybody else?

Sorry, I lost my place. Do individuals work outside the setting in integrated community setting.

I think that should be reported too.

I agree with Victor.

This is Kyle. What kind of context are you thinking about rewording?

Well, it's like an all or nothing the way it's written.

Okay.

And we need to talk about –

This is Terry. We need to integrate it as open to interpretation even though some would suggest it as I believe it is.

Reword it.

Number 6.

You could have a definition of that (inaudible).

Right.

That could be more than one question.

Right.

Number 6. If individuals desire to work and an integrated community setting, are there processes to ensure the opportunity is pursued. I can't hear anyone.

Yes.

I can say yes but. Is there a curfew or any other requirement for scheduled return to the setting.

Curfews.

Yes.

Yes.

Doing a happy dance (chuckling). Let's keep going. Individual assessments. And we are going to talk about whether or not we are going to create one of these for Delaware at a future meeting.

Send another document?

Have it?

That's another South Dakota?

Yes. It says self-assessment, individual assessment, and it has this colored –

Is that a two pager?

Yes, that one. That Laura has. One, two, three, four. So a four page document.

Is it the first page?

Yes.

Yes, it's a two pager, but it's a four-page document.

What's the first page look like? This is stapled altogether.

Did you choose where you currently live is the first question.

You gave me the staff assessment.

It says individual assessment at the top.

It starts in the middle of a –

The first question is, did you choose where you currently live.

This is Terry. A broader question here is what we are going to do with nonverbal persons. Just a comment. Maybe a parking lot issue?

Yeah. I was just waiting for everybody to find the document first.

Bill, do you –

I don't have it.

This is Terry. I think it is two pages that I have.

There's another one.

This is Tim. There are two here, there is a settings assessment and in individual assessment. We're starting on the settings assessment, and I have a concern about number 1.

I thought we were doing individual.

We are doing individual.

Okay, you just said start on the settings.

Oh, I'm sorry. My mind left me about 20 minutes ago. (Chuckling)

We talked about this before right off the bat that an awful lot of people including my son got assigned to where they live, and the vast majority of people did, so I would want to add something about timing here or history or something that would allow for somebody reading the document's answers to understand that up until very recent times, the individual was not allowed to do his or her own assignment.

This is Terry. Maybe a more germane question would be, would you choose to live here if you had that choice today, or something to that effect.

Okay, and might I just point out on the page behind, Tim, we are going to cut we need to discuss this. We need time to discuss this issue of how we are going to address – Nonverbal persons.

Or no, people who moved into a place that didn't have choices because – 20 years ago

Yeah, and how we are going to address that because that's not in the individual assessment, it's in the provider assessment as well.

This is Kyle. That may be the case, and that is the history, but the whole purpose is assessing what is currently going on to not meet these new CMS guidelines. So I think everybody does know that there was a certain process before, which may be didn't allow for this, but we are moving to a new way of doing things. CMS is putting out guidelines to do that. So I think it's important that we keep something like that, whether you want to add some kind of preamble to it or preface to kind of try things, but I think that that is a good question to meet the CMS guidance.

This is Libby. I think we're all in agreement with you, I think we just need some time to put the words together on that one.

Sure.

And I don't think we're going to have time to go through this will document today. How about if we talk just a little bit about how people are feeling about doing, do we want to create an individual assessment along with the provider assessment? Some states have done this and some states haven't. Does anybody have a feeling about -

What were we asked or charged with? Was it just looking at the assessment to determine if we want to have both or are we tasked with doing settings assessment or -

Will assessment be asked of everyone who is a client of DDDS or or just those folks who are living in residential sites? Because there are many more of us out there whose family members live at home who may need services but aren't getting services and may be unhappy with -

This is Tim. This group just deals with residential.

Yeah, and we addressed that last week.

This is Tim again. For Kyle's question, our task was to develop by June 15, primary task, a self-assessment for providers. That's the way it was given to us. But then some of the state documents we received had these additional pieces to them, but not every state document did. So I think Libby's correct. It would be up to this group to decide whether the state should add on, I hate the word consumer, a person assessment document.

This is Terry. I just wanted to ask Fran if there isn't some sort of individual assessment that was already done within the DDDS system.

This is Fran. We actually have the NCI data that's an individual survey. The problem that might pose for this group is it does not break responses out by program or facility, so we'll have data that

will answer many of these questions next spring, but we want to be able to tell how many of these responses are specific to each facility, and we do a sample, we don't do 100%.

This is Terry. I think the scope of our current mission or purpose is already really brought it is going to be very challenging. I would like to suggest that DDS look at the issue of talking with the individuals and assessing their perspective on these issues as part of the look behind process or that at some point in the future we could say that's something that should be done or done differently or done better at some point in the future but we just didn't have time for it.

Okay, Kyle.

Yeah, since we asked the question, and the more I'm thinking about it, I'm thinking it is if we do have the time. Maybe we are tasked with doing that one percentage copy this isn't all that detailed, and we might not have time today but I think it would be very beneficial that we did if we can develop an individual assessment.

This is Lisa. These two documents are the exact same questions that are in this that the provider is going to be answering. I think these settings assessment is not necessary because it's in here and these are exactly the same. The individual assessment I might not have a problem with, but I think we may need to come up with a tool that the providers are going to have to use and what proof you're going to ask of us, because if we have to show proof, to some of these questions, then we might not need this tool right now. Because you are giving all the providers may be what, three months to complete this. That's a lot to do in addition to, so I don't think the individual assessment is a bad tool, but we could talk about the timeframe that they want all this turned around.

This is Terry. Again I think the scope of what we have to do with the facility or the setting assessment is already daunting.

This is Victor. I don't think it's a question of the individual being a tool where you said I don't think it's a bad tool, Lisa. I don't see how it could not be a positive tool. I don't see how it could not be because it gives an entirely additional layer of information and I would think could only add to the credibility of whether facilities are or are not in compliance.

I think it's just going to take more than three months. I don't have a problem with it. I think the agency's are not going to be able to do this in three months once we get the tool.

Kyle?

I think Victor made a very good point. We talked about what we are tasked with. What do CMS require? Doesn't CMS require one of these?

Short answer is no.

Again CMS is requiring a process to be in place. Each state is determining the assessments and how those assessments are done.

This is Libby. I think if we are going to do the individual assessment, that would come after we are pretty finalized on the agency other assessment because once we have those questions nailed down and we are all happy with them we can say okay let's put those in a different perspective, so maybe we could focus on residential or agency assessment and then see where we are timewise.

I agree.

Why would the agency be asking the individual these questions?

That's a good question. This is Terry.

It's certainly invalid.

That's why the look behind becomes a more valid mechanism for asking this questions, it's an independent party.

This is Libby. Fran, in the Delaware document it said something about the national core indicators it mentioned earlier, that we have to use those as part of the survey process, and I don't really know

what that means.

This is Fran. So the national core indicators is a survey, it's a 25 page survey. It is done individually with adults in the DB system. University of Delaware right now is doing the survey with adults. In order to participate we need to have a minimum of 400 surveys completed. Many of these questions are asked in the NCI survey and to the state again for our internal review process will use NCI data where again it may become problematic for this group, as I said to Terry, is that when we get the data back, we want to be able to slide responses with agencies. So for instance if there's an agency in their assessment, self-assessment is going to say we have 100 percent satisfaction for the last year. We'll have X number people say yes, there are 100% satisfied, but we know if they match the agency who said 100%.

So in this document it says that date is going to be used as part of the survey process. How do you see it fitting end? Should we –

This is Fran and I think there's a self-assessment being done by the individuals. It will not be 100% in the NCI survey is that client satisfaction, individual assessment.

This is Laura. It's a separate assessment, it doesn't really have anything to do with what we are doing.

It does not have anything to do with what we are doing. This is Fran. It does have something to do with what we are doing. CMS is very supportive of the NCI survey. They understand the data.

We'll be looking at NCI data to compare to what data is coming back from the agencies, if there's any disparities they're going to ask us to go back and try to figure out the reason for that.

Now I mean in terms of developing this particular instrument, that's –

Where the agencies in particular?

Yeah.

I would say not as much as if you intend to create an individual survey, so there's an individual survey right now that's being done right now. We will have data this time next year. But we won't be able to break it out agency by agency.

So our time is just about up. This is Libby. As far as the action items from today's meeting, we only have one written down. Did anybody take note or –

I volunteered to try and find a human rights assessment.

Fran, you are going to get some of the ELP's or –

Yes.

Laura was going to send that link.

Um hm.

While Tim's writing the next meeting is next Thursday 130 same room, if you have agenda items, what else? Laura is going to send a link.

Federal registry, right?

Federal registry.

Thank you for that.

The comments are actually pretty, how they respond to the comments that were made, and that's part of the big huge 94 pages but that's actually pretty helpful.

Fran is going to provide us an example of the ELP.

The ELP, the ISP. And information on Probus and the (inaudible).

Could you do that ASAP?

Libby, you will share the full list of section items for future –

Yes, now if we can just take one minute to talk about next week's meeting. If Melinda and I are able to pull these documents together, is that we want to focus on or should we start pulling some



of these discussion topics onto the agenda?

This is Terry. I really like that idea. It does this the way I think. The idea of pulling together all the various questions on each individual topic. I think it was it was a bunch of time if we could start identifying which one we like best.

Okay, and then I was sent out this list and if it looks like one of those seems really important to get on the agenda for next week just let me know. Does that work?

Sounds good.

Okay. Anything else? And I'll take this up and send it out.

This is Gary. Are we going to table the individual assessment until next time? I don't want to belabor it, but I agree with the settings. It sounds like it's already in there. It wasn't quite the staff assessment, which is this? I was a little confused by the title.

I think we agreed to table it until after we get a handle on the agency assessment at this point. All right. Thank you very much. Time's up.